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# Re-engaging with places: Understanding bio-geo-graphical disruption and flow in adult brain injury survivors

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## ABSTRACT

Acquired Brain Injury (ABI) is one of the most common causes of disability and death in adults worldwide. After a period of rehabilitation, many ABI survivors still face complex mind/body conditions when they try to take up their former life again. Besides lasting visible impairments such as weakness and loss of body balance, there are often less obvious disabilities such as extreme fatigue, hypersensitivity for stimuli, memory, concentration and attention problems or personality changes. The aim of this paper is to understand how ABI survivors and their significant others renegotiate their engagements with everyday places, using the concepts of bio-geo-graphical disruption and flow. We conducted in-depth interviews and did a place-mapping exercise with 18 adult ABI survivors and their significant others. The data were analysed according to the principles of thematic analysis, with use of Atlas.ti. In the struggles of ABI survivors' relations with place, our findings show diversity in personal experiences and strategies, as well as commonalities at a more general level. First, having access to meaningful places, old and new, and coming to terms with the fact that some places may not be accessible anymore, appeared to be vital in the participants' process of healing. Second, the interplay or, as we call it, reciprocity, between different places can contribute to wellbeing: for instance, the security and continuity found at home may enable ABI survivors to handle a trip to a crowded city centre. Thus, by framing mind/body problems of ABI survivors in terms of a network of meaningful places rather than as a body with lost functions, our study shows how the reciprocity between multiple places has a potentially positive effect on life post-ABI.

## 1. Introduction: the disabling consequences of acquired brain injury

ABI refers to a sudden damage to the brain, as a result of for instance a stroke, tumour, traffic accident, or fall (Grace et al., 2015). Its disabling consequences are diverse, and depend on the cause, severity and place of the brain injury. They range from visible physical limitations such as walking problems and a dysfunctional arm, to invisible cognitive impairments and behaviour problems. Invisible impairments include concentration and memory problems, reduced pace of information processing, lack of insight, and extreme fatigue. The plethora of consequences results in different challenges in everyday life for each ABI survivor and the people around him or her, related to daily activities, mobility, communication, changed sense of self and feelings of loss and grief (American Stroke Association, 2017; WHO, 2006).

In the Western world, most ABI survivors receive some form of rehabilitation, which typically starts in hospital, and is followed by short-term rehabilitation in hospital, longer term rehabilitation in a

specialised rehabilitation clinic, or outpatient settings. Treatment by a multidisciplinary team and support for informal carers are seen as key features of rehabilitation (WHO, 2006). The efforts of the multidisciplinary team are typically evaluated with use of independence and mobility measures (Proding et al., 2017). However, despite increased awareness of the long-term consequences of ABI, the complexities of life post-discharge are underestimated (Nanninga et al., 2015).

After in-patient rehabilitation, ABI survivors often experience restrictions in their participation in society (Fallahpour et al., 2015; Schipper et al., 2011). Because of their impairments, the amount of activities they can undertake on one day is limited (WHO, 2006). The environment, or, in geographical terms, the places where activities happen, can have characteristics that are experienced as enabling or disabling for ABI survivors. These entail physical aspects such as ramps and uneven flooring, as well as social aspects, such as crowdedness and the presence of other people with whom some form of social interaction is required. So, survivors often have difficulties re-engaging with places that were important pre-ABI, which may lead to identity confusion and

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feelings of loss (Meijering et al., 2017). In this context, the aim of this article is to increase understanding of how ABI survivors and their significant others renegotiate their identity and engagements with everyday places. This understanding may change the way we think about rehabilitation medicine, especially post-discharge.

## 2. Theoretical framework

### 2.1. Identity after ABI: biographical disruption and flow

The idea of biographical disruption was developed by Bury (1982) and refers to the 'break' in one's identity that people may experience after a sudden life-event, such as brain injury due to a stroke or accident. Upon brain injury, and especially when the effect of the injury-related impairments on daily life manifest themselves, a survivor may feel that the life s/he was leading, and had envisaged to lead in the future, may not be possible anymore. As a result, ABI survivors can experience intense changes to their identity (Gracey and Ownsworth, 2011) since they may not be able to continue their employment, hobbies, or family life (Hoogerdijk et al., 2011; Nochi, 1998). The discussions on biographical disruption and identity change after ABI resonate with notions of the "lost" or "shattered" self that have received much emphasis in the literature on ABI (Medved and Brockmeier, 2008).

However, more recently, it has been argued that experiences of the self after ABI can also be characterised by continuity, such as in terms of personality, cognition, emotions and abilities. Gelech and Desjardins (2011: 68) demonstrated with a small sample of ABI survivors that "the essence of who they were had remained intact". Their participants acknowledged that aspects of their selves, such as physical or cognitive abilities, had changed. However, they strongly felt that their "inner self", or the core of their identity, remained unchanged. The idea of continuity of the self after ABI resonates with the idea of biographical flow, which refers to the idea that there is a continued sense of self after ABI that aligns with one's pre-ABI identity (see, for example, Faircloth et al., 2004). This accords with Harvey's (2018) work on everyday life post-ABI, in which he prompts a more positive view of lives after ABI that are often seen as 'damaged'.

### 2.2. Engaging with places after ABI

A recent addition to the literature is the bio-geo-graphical perspective, which focuses "on the extent to which relational experiences of space/place are disrupted by changes in the life course arising from disability as well as by how taken for granted embodied states have to be renegotiated at any other place anew" (Meijering et al., 2017: 7). This bio-geo-graphical perspective combines a spatial and temporal perspective on the experiences of ABI survivors, as it looks at changes in survivors' experiences of meaningful places pre- and post-injury. A changed identity may be played out differently in different places, as disruption may occur in one place, and flow in another – which supports the idea of an identity that is lost and continued at the same time. The bio-geo-graphical perspective thus shifts focus from sense of self to sense of place. ABI-survivors may make sense of themselves in terms of the meanings and felt experiences of activities in different places.

When considering the idea of meaningful places before and after ABI, it is worthwhile to delve deeper into how these meanings come about. To achieve this, we use the concept of sense of place. Grounded in humanistic geography of the 1970s, sense of place has been used to encompass the meanings of and experiences of people in places, thus including more than the physical aspects of places (DeMiglio and Williams, 2016). Thus, sense of place can be described as the meanings that people ascribe to places they know by experience. Drawing on Kyle et al. (2004) and Bell et al. (2015), we disentangle the concept of sense of place into four dimensions: 1) place attachment, or the affective dimension, comprising emotional attachments to place; 2) place identity, or the cognitive dimension, which is about how places define

people's sense of self; 3) place dependence, or the behavioural dimension, which concerns how places facilitate the undertaking of meaningful activities; and 4) social bonding, or the social dimension, which emphasises how places may support (or thwart) interaction with other people. In this paper, we use the concept of sense of place to explore how the bonds between people and places may change post-ABI in everyday life.

When looking at the bonds with and participation in particular places that people renegotiate post-ABI, it is useful to distinguish between the home, and the broader community. Typically, the home can be adapted, especially in terms of its physical characteristics. Ideally, the home becomes a place where ABI survivors can participate in everyday activities, and be comfortable again (Galvin et al., 2010; Meijering et al., 2016; Nanninga et al., 2015). However, the sense of home of many ABI survivors and their significant others, may remain disrupted too (Eilertsen et al., 2010). Especially problematic to re-shape are often the social routines, roles and relations within the home because of the changed life-paths and identities of both survivors and their significant others (Kirkevold et al., 2014). Places in the community are more difficult to adapt, as they may have physical and social design aspects that confront ABI survivors with their impairments (WHO, 2006). For instance, traffic lights may not accommodate the time that ABI survivors need to cross a street; and walking partners may not be aware of the concentration and effort it takes to deal with (in)visible impairments in crowded places (Nanninga et al., 2017). Hence, participation in community life is experienced as extremely difficult by ABI survivors (Gelech and Desjardins, 2011; Trexler et al., 2010). In an article on 'insider perspectives' on participation after ABI, Schipper et al. (2011: 836, original emphasis) found that participation is about "taking part, giving something and being someone in a specific context". When ABI survivors experience their participation as restricted, this is especially problematic when the restrictions pertain to activities that contribute to a sense of meaningful participation in society (Schipper et al., 2011). This discussion ties in to ideas from the literature on geographies of disability, how 'ableist' spaces can actually stress and worsen people's impairments (Crooks et al., 2008). At a more general level, this aligns with Harvey's (2018: 90) sociological perspective, which emphasises how disability should be contextualised into a person's whole life, by "viewing life as fluid and ever-changing".

### 2.3. Study design

This article is part of a larger project on home- and place-making of adult ABI survivors and their significant others. Participants were recruited through an in-patient ABI rehabilitation unit, where our participants had worked on their recovery after being discharged from the hospital. The criteria for entry into the rehabilitation unit are moderate to severe disability and multifaceted problems due to the brain injury. All 18 participants lived in the provinces of Groningen and Drenthe in the Northern Netherlands and were aged between 30 and 75. Our participants included nine men and nine women. Fifteen participants had experienced a stroke, three had acquired brain injury after an accident. Four participants were engaged in paid employment, one was retired, and the others were assessed as unable to work for the remainder of their working lives by an independent physician. All participants were interviewed in the presence of a significant other, often their partner. An overview of the participants' characteristics can be found in Table 1.

In line with the interpretive paradigm underlying the research, we adopted a qualitative methodology (see Hennink et al., 2010). We combined semi-structured in-depth interviews with place-maps (see below), to allow for in-depth understanding of ABI survivors' changed and changing experiences of place. The ABI survivor and a significant other participated in an in-depth interview, at the end of which the place-mapping exercise was carried out. A research assistant (NT) conducted the interviews and place-mapping. The concepts of bio-geo-

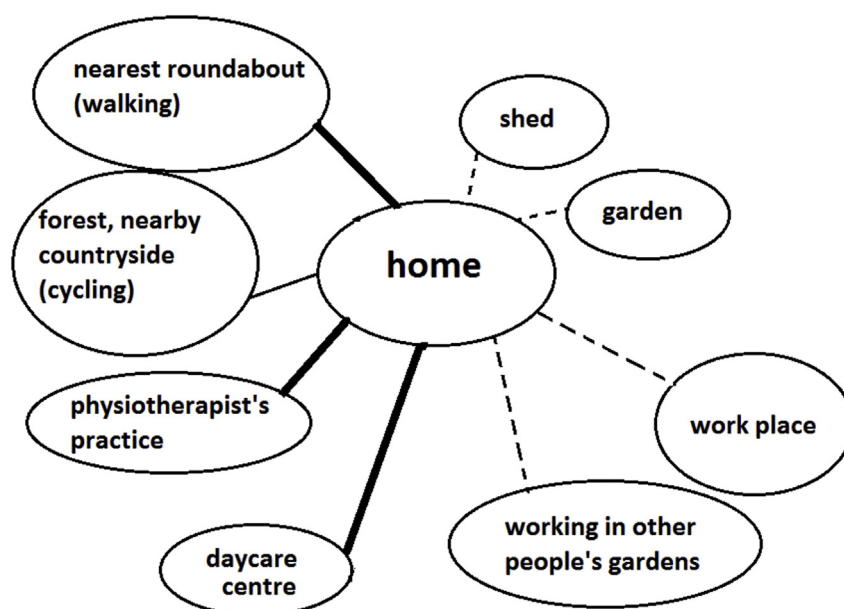
**Table 1**  
Study participants.

	Name	Age	Marital status	Living environment	Socioeconomic status	Work	Neurological condition
1	Johan	60–65	Married, two adult children	Urban residential neighbourhood	Average	Incapacitated	Stroke
2	Toon	50–55	Married, two children, one adult, one at home	Remote farmhouse	Average to high	Incapacitated	Traumatic Brain Injury
3	Jan	60–65	Married, two adult children	Farmhouse in a village	Average	Incapacitated	Stroke
4	Wim	60–65	Married, two adult children	Urban residential neighbourhood	Average	Full-time work	Traumatic Brain Injury
5	Harm	70–75	Married, two adult children	Urban residential neighbourhood	Average to high	Retired	Stroke
6	Wanda	55–60	Divorced, four adult children	Village	Low to average	Incapacitated	Stroke
7	Eva	35–40	Married, one child at home	Urban residential neighbourhood	Average	Part-time work	Stroke
8	Jeannette	50–55	Married, no children	Village	Average	Part-time work, self-employed	Stroke
9	Coby	60–65	Married, two adult children	Temporary chalet	Average to high	Incapacitated	Stroke
10	Marion	30–35	Married, two children at home, one stepchild part-time at home	Urban residential neighbourhood	Average	Incapacitated	Stroke
11	Abe	55–60	Married, two children at home	Houseboat in remote area	Low to average	Incapacitated	Stroke
12	Gerda	50–55	Living apart together, one child at home	Village	Average	Incapacitated	Stroke
13	Geert	55–60	Married, two adult children	Village	Average	Incapacitated	Stroke
14	Inge	35–40	Living apart together, one child at home	Village	Low	Unemployed	Stroke
15	Dorothea	60–65	Married, one child at home	Village	Average	Incapacitated	Stroke
16	Ruud	40–45	Co-habiting, one child at home, one child at home part-time (co-parenting)	Urban residential neighbourhood	Average	Fulltime work, self-employed	Stroke
17	Irma	50–55	Single, one adult child	Village	Low to average	Sick leave	Stroke
18	Harry	60–65	Married, one adult child	Village	Low	Incapacitated	Traumatic Brain Injury

graphical disruption and flow served as a deductive starting point in developing the interview guide, which is available as Supplementary Material in [Appendix A](#).

We designed an exploratory qualitative method which we called ‘place-mapping’, which we applied during the in-depth interviews. This method can be labelled as a participatory visualisation technique and a type of mind-mapping ([Kindon, 2010](#)). A place-map is a schematic representation of the places important for a person, and of the connections between these places (see [Fig. 1](#)). At the end of the interview, the interviewer would write down the places that had been discussed, and the participants would add the importance of those places, the mode of

transport, and additional places that had not been discussed previously. The place-mapping exercise served to make sure that the data were grounded in the participants’ experiences, since working on the place-map served as a moment of reflection during the interview. It encouraged participants to think about whether all important places had actually been discussed, how these places were (dis)connected, and whether they wanted to add information on some of the discussed places. Also, experiences of flow and disruption were visualised by adding filled and dotted lines. Overall, the place-mapping exercise enhanced the validity of the data ([Babbie, 2013](#)), as it helped to establish whether all important (lost) places and connections had been discussed,



**Fig. 1.** Example of a place-map (Jan, see [Table 1](#)). Dotted lines represent places that are no longer accessible; Bold lines represent new places; regular-font lines represent places that have remained the same pre- and post-ABI.

from the perspective of both the ABI survivor and his/her significant other. In three cases, the place-mapping exercise was not carried out. In one case (Coby), the participant was too tired, and in two other cases, work used to be the only place that the participant frequented outside the home. For one participant (Ruud), the frequented places stayed the same; for the other (Harry), home became the only place where he spent time post-ABI. In both cases, place-mapping was not necessary to understand which places were important and how these were connected. Perhaps more importantly, we felt that drawing place maps would be too confronting for these participants.

The interviews were transcribed verbatim. Data-analysis was conducted according to the principles of thematic analysis (Joffe and Yardley, 2003), with use of Atlas.ti, by all three authors. Each interview and place map was coded and analysed independently by two people (LM/NT; and LM/AL), which meant that the experiences of flow and disruption were categorised for different places and activities. Then, these findings were discussed until consensus between the two coders was reached. After the findings had been agreed upon among the coders, the emerging findings were discussed amongst the complete team of authors and finalised.

All participants were informed about the study in person by a rehabilitation professional, and through an information letter. The interviews lasted between 60 and 140 min, and the interviewer asked the participants whether they wanted to take a break from time to time, to prevent risks such as fatigue, strain and distress. In one case, the interview could last for a maximum of 1 h, because of fatigue. Another interview needed to be stopped at various moments in time, because the participant needed to take her blood pressure. For many participants, re-telling and reflecting on the story of their ABI, period of rehabilitation, and return home, was an emotional subject, and seemed to have a therapeutic effect for some. The interviewer had regular 'debriefing' sessions with one of the senior researchers involved (LM), to discuss and reflect on the often difficult stories she encountered. Besides functioning as an outlet, these talks also served as a starting point for the data-analysis. Ethical approval was acquired from the Ethics Committee at the Faculty of Spatial Sciences, University of Groningen.

## 2.4. Findings: narratives of bio-geo-graphical disruption and flow

Table 2 presents an overview of the experiences of our participants in different important places and activities: the body, home, work, leisure and holidays. We categorised each of these places and activities as being dominated by flow, dominated by disruption, or characterised by alternations of both. When analysing the participants' stories, we found that these are hardly ever dominated by either complete flow or disruption. Rather, it became clear that disruption and flow alternate, both within and between places.

The diversity in experiences illustrates the fragmentation of the embodied experiences of ABI survivors in different places. We will unpack this further in the next sections of the findings, in which we discuss meaningful places that have been maintained, lost, and regained. In so doing, we also elaborate on how these places are (dis)connected.

## 2.5. Giving new meaning to previously comfortable places

Sixteen of our participants had to renegotiate the meaning of the home in the light of post-ABI impairments. The physical home sometimes had to be adapted, due to the participants' physical impairments. These adaptations included, for instance, creating a downstairs bedroom, or installing grab bars in the shower or on the stairs (we have discussed these more elaborately elsewhere, see Meijering et al., 2016). In some cases, feelings of bio-geo-graphical disruption, alternated with flow, persisted after physical adaptations had been made. This occurred, for instance, when participants were unable to access all parts of the home (Wanda; Marion; Dorothea), and/or when they were feeling

insecure in the context of their impairments (Eva; Gerda; Dorothea). Although important, these physical adaptations were less significant in re-establishing bio-geo-graphical flow than the adaptations made to overcome the barriers associated with invisible impairments. What emerged prominently from our analysis, was that fatigue and sensitivity for stimuli are vital invisible barriers in engaging with places in everyday life. For instance, Geert and his wife decided to use one room in their home for Geert as a place to withdraw when he is tired:

Geert's wife: You have a room upstairs where you can withdraw, so that I can receive visitors. And now you can bear some people around you, since you stopped working. But when it becomes too much, you can go to your own place upstairs [...] You use it, I had a visitor recently and...

Geert: Two women, and all the chit chat, it drives me crazy.

Geert's wife: It's quickly too much [for him] and then he goes away, either upstairs, or take a walk.

Interacting with visitors is something Geert does enjoy, but he tires quickly. Now, his wife can continue to receive guests while Geert is upstairs in his room. Adapting the use of space in their house has enabled them both to enjoy their social life within the home again. Furthermore, it demonstrates how one place (the living room) functions as a place for social interaction, and another (the upstairs room) as an escape for this. This example demonstrates how the re-negotiation of physical places positively affects Geert's and his wife's place identity with regard to their home. Similarly, most participants invested energy in accommodating their homes to their invisible impairments. For most, this resulted in experiences of flow in the home, which is important as the home was typically the place where they spent much of their time.

Our participants were often challenged in reaching and giving meaning to the places where they previously had enjoyed spending time. Marion, for instance, liked going to petting zoos, parks and forests with her daughter before she had a stroke. During her rehabilitation, she learned to cycle again, using a tricycle. She also tried using a mobility scooter, but she disliked the fact that she could not carry her children along on either of these. Hence, she decided to save up the money to purchase an electric cargo bicycle:

Marion: It turns out to be really easy and I can bring my children with me in the bike. I am really pleased with it. It has enlarged my world: I can now independently visit friends and acquaintances, which I couldn't do for two years. Now, I am able to go wherever I want. [...] We go to see animals, deer especially. And we also go to the petting zoo, the kids love it. I used to do that with the eldest and now I am able to do it with both of them, so in that sense, I'm not missing out on anything. [...] I have my life back.

With the cargo bicycle, Marion is able to go to the places where she likes to go, and to enjoy leisure activities with her children. Still, Marion's story also opens up questions about unequal access to tailored modes of transport: she did not get social support to buy the bicycle, and had to save the money for it herself. Although Marion was, in the end, able to save the money, this will not be feasible for everyone, and we thus conclude that there are inequalities among ABI survivors, in terms of the access they have to different modes of transportation, and with that in terms of accessing meaningful places as well.

## 2.6. Opening up new meaningful places and activities

Places and activities of pleasure and leisure were often disrupted at first, as participants had to give up hobbies such as sailing, motorcycling, and shopping, because of their ABI-induced impairments. Many participants (13) therefore opened up new meaningful places for social leisure activities. An example is Inge, who chose to become more focused on her family in her social activities, because of the extreme fatigue that has become part of her life:



**Table 2**  
Places and activities of flow and disruption<sup>3</sup>.

ID	Pseudonym	Body	Home	Work	Individual Leisure <sup>1</sup>	Social leisure <sup>2</sup>	Holiday	Total places dominated by disruption per participant
1	Johan							2
2	Toon							1
3	Jan							2
4	Wim							0
5	Harm							1
6	Wanda							5
7	Eva							1
8	Jeanette							1
9	Coby							2
10	Marion							0
11	Abe							1
12	Gerda							1
13	Geert							2
14	Inge							2
15	Dorothea							2
16	Ruud							1
17	Irma							2
18	Harry							4
<b>Total dominated by disruption per place</b>		<b>9</b>	<b>2</b>	<b>7</b>	<b>6</b>	<b>3</b>	<b>3</b>	<b>30</b>

<sup>1</sup> Individual leisure includes activities such as doing sports, knitting, crafting, walking, gardening

<sup>2</sup> Social leisure includes activities such as going to restaurants, bars, birthday parties, and family gatherings

<sup>3</sup> Explanation of the fill colours: black - disruption dominant; medium grey: both flow and disruption in one place/ activity; light grey: flow dominant; white: unknown

Inge: Resting, well, a lot of things, hospital, physiotherapy, and taking a rest. [...]

Interviewer: You are working on improving your health.

Inge: Yes, I walk the dog a couple of times per day. [...] Then I walk a big round, and have dinner [at my parents'], I eat there three times a week. With the four of us, my parents [and my son].

Her parents' house became an important place for Inge, as her parents cook for her and her son three times a week, whereas they used to do this only once in a while pre-stroke. Furthermore, she aims to walk to her parents', as part of her attempts to improve her physical health. For Inge, the house of her parents became a place that serves as an escape from her own house, since she has difficulties managing the household chores in her own house, in combination with the care for her young son. Other participants told similar stories, of how they were supported by family members, friends, and sometimes neighbours, which opened up access to and experiences of new place dependent activities.

For Harm and his wife, the idea for developing new leisure activities originated in one of the therapies Harm was taking:

Harm: Yes, I used to have therapy, and that was about, with a [speech therapist], and she, she accompanies you with a guitar and then try to ...

Harm's wife: Shall I?

Harm: Yes, go ahead.

Harm's wife: Try to sing the practical and everyday things. So he had to sing it, together with the speech therapist, and in the end on his own. There he had learned something practical, like can I have two cappuccino with apple pie. And he could do that when ordering in a restaurant, two cappuccinos and two apple pies. [...] He had to practice, and you don't have a lot of options at first. So cappuccino and apple pie it was.

Interviewer: [...] So, where did you go?

Harm: Different places where we could go.

Harm's wife: Now we know where they have the best coffee. [...] And we still go there.

Ordering cappuccinos and apple pie had begun as a way to practice Harm's speech. Gradually, however, this became part of a new leisure activity for Harm and his wife. They created a habit of making cycling tours, Harm on his tricycle, and his wife on her bicycle. During breaks, they would sit down some place, and order coffee. Thus, they incorporate drinking coffee into their already existing pass-time of making bicycling tours of the surroundings – creating natural moments for Harm to recuperate (see Fig. 2). In this manner, they achieved a sense of bio-geo-graphical flow in their leisure time.

When considering holidays, as a particular type of mobility through which places are connected, it became clear that six participants faced

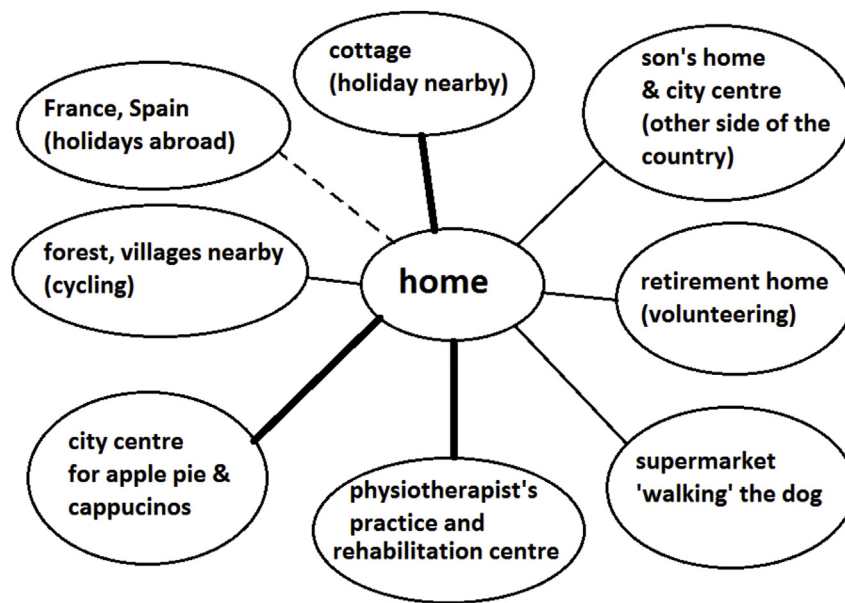


Fig. 2. Harm's place-map, now including apple pie & cappuccinos at the city centre.

barriers. For Gerda, for instance, it is too challenging to ride in the passenger's seat of the car:

Gerda: We [partner, his daughter, and Gerda] went on holiday to France, my first long drive. It went really well, I was very tired but it went well. I did not sit in the passenger's seat. But in the back. The first couple of kilometres I sat in the front, and then we took a break, and I said, well I'm gonna sit in the back, because I'm getting too many stimuli. I sat in the back, and it was perfect. [...] We took our time and drove in three days [...], but it was tiring. Still I thought it went really well.

Gerda was able to adapt her way of travelling, as she realised that travelling in the backseat of the car would be more comfortable for her than sitting in the front. In the end, this opened up new places for her. Other participants voiced similar experiences in the sense that they had adapted their way of travelling to their holiday destination, or the destination itself. Some participants chose to celebrate their holidays closer to their home, or in a different type of accommodation. For instance, Harm and his wife decided to cycle to their holiday destination, since that enabled them to bring Harm's tricycle along. In terms of accommodation, Dorothea and Marion chose to spend their holidays in a cottage, rather than going camping. In these manners, our participants managed to overcome the potential barriers associated with holiday-making. Some of our participants did not have the possibility to go on holidays, often because they could not afford it. These participants were more home-bound in general than those participants who could get away. From the participants' stories presented above, the relationality of different places emerges. We discuss this in more depth in the next section.

## 2.7. The interplay between engagements within and between different places

Twelve participants struggled to get back to (paid) work, because of their impairments. Those participants who had enjoyed going to their work place, and who often derived a large part of their identity from their employment, seemed to struggle to realise how their impairments acted as barriers in performing their work properly. Before his brain injury, Geert had a very busy working life as a company director. After rehabilitating, he went back to work for almost a year, part-time at first, but soon working full-time again. Geert struggled, but his colleagues helped him and he persisted. At work, he did his best, but at home, he

was so tired that he could not do anything anymore. This resulted in experiences of disruption at his home place, both for himself and his wife. In the end, the situation became unsustainable, and his wife explained what happened:

Geert's wife: The general practitioner had already stressed that you should stop [working]. In November, you experienced failure on the right side of your body again. [...] It got better, and you got back to work, but in January you were on your way to work and you forgot where you were, you were confused. Then, ultimately they said that you had to stay home. They had said it before, but he wanted to go to work.

For Geert, his job was such an important part of his identity, that he could not quit until other people literally forced him to stop. This brought on a disruption in his working life as he missed both his work place and the activities associated with it. He had to re-negotiate the part of his identity, and was searching for other meaningful activities, especially in and around the home. He discovered that he enjoyed gardening, but was worried about the upcoming winter, without significant gardening chores to keep him occupied.

The interplay between disruption and flow in different spatial settings was also prominent in Toon's story. At the time of the interview, Toon was living with his wife in their large farmhouse where his wife keeps two horses. Three years ago, Toon experienced brain injury after a violent conflict with one of his neighbours. Toon talks about his home as "my own place, my own castle". He is proud of his house and told us how he had longed to return when he was hospitalised. However, Toon has difficulties in feeling at home again in his house. The most significant barrier to this lies in and around his home itself, as the violent accident happened directly next to their home. Toon prefers not to encounter this place:

Interviewer: Were there any places in your home where you did not want to be, after you returned home?

Toon: Yes, there. [points in a direction]

Toon's wife: Where the accident happened ...

Interviewer: How did you do that, because, do you have to get out the house from there?

Toon: We always go out that way, through the shed.

Interviewer: Did you do that beforehand as well, or did it change?

Toon: It changed.

Toon's wife: We have to go out the other way if we are going by car ... But it's difficult.

Toon's post-injury homemaking process has been difficult due to the complex circumstances discussed. Thus, despite what he says about his home as his castle, his home is no longer a site of ontological security. Rather, it has become a paradoxical place: a place where he deeply enjoys being, but also a place where he does not want to be. Besides resulting in contrasting and even conflicting experiences of home, the consequences of his injury also hinder Toon from carrying out his favourite leisure activities. Toon calls himself a “water person” and used to find tranquillity and peace in undertaking activities such as sailing and diving before he had the brain injury. However, after the brain injury, he is no longer allowed to dive and his fatigue and slower reaction time make it difficult to continue sailing. He has tried swimming as a substitute leisure activity, but the bustle, noise and bright lights in the swimming pool have made the experience unsuccessful.

Toon and his wife did, however, find a way to reincorporate the water into their lives, since they purchased a second home by the sea. In this context, it needs to be noted that Toon and his wife are quite well-off financially; this implies that some of the coping mechanisms they employ would not be open to less affluent people. They mentioned that they enjoy going to their second home mainly so that they can relax and ‘recover’, away from the partly negative thoughts and memories in their first home. This is illustrated by the central position of, and arrow between, both homes in Toon's place-map in Fig. 3. Furthermore, Toon said:

[I]t's about being able to simply walk to the dikes, to walk along the mud flats, so that you can look from there, see the lighthouse, that is just ... well. [...] No one knows you, there. You don't have to explain what's going on. They don't know. That's good. That you can be anonymous.

The second home is a way for Toon to escape from his everyday life in the farmhouse. These temporal escapes enable Toon to face his anxiety when he is in the farmhouse. However, overall, the reciprocity between the farmhouse and the house at the sea enables Toon to work on the embodied and geographical disruptions that he experiences. This reciprocity between places gains depth when we consider its meaning

for Toon's wife as well. She prefers to live in the farmhouse, because she can keep her horses there. As a result of that, Toon and his wife decided to continue both living in the farmhouse and the house at the sea, rather than moving to the sea fulltime. Although they have found an equilibrium in living both at the farm, and at the sea, ‘complete’ bio-geographical flow has not been established. In conclusion, Toon's experiences illuminate how experiences of flow in a particular place (second home) may help to take on the challenge of living in a place of disruption (first home). This foregrounds the idea of reciprocity between places.

### 3. Discussion

This article aimed to increase understanding of how ABI survivors and their significant others renegotiate their engagements with everyday places, in terms of bio-geo-graphical disruption and flow. We found that these engagements were characterised by loss, disruption, gain and flow at the same time. This entails a shift in focus away from what is lost, towards potential and what the future may hold (Harvey, 2018). This vision of ‘becoming’ can be specified in a network of places that ABI survivors wish to explore, where they want to interact in a fluid, dynamic and balanced way, by taking into account their (dis)abilities. The most significant barriers experienced in engaging with places were extreme fatigue and sensitivity to stimuli. These barriers are invisible, and hence often difficult to understand for other people, both intimi and strangers (McCarthy and Lyons, 2015). As a result of these barriers, ABI survivors renegotiated their engagements with everyday places in multiple ways.

Overall, it is too simple to say that a person's story is dominated by either disruption or flow; the picture is much more refined and complex and disruption and flow occur both between and within different places. First, our participants renegotiated their relations with existing places, in close connection with the social relations associated with these places. They cannot engage in all activities they want to, so they need to prioritise. For instance, maintaining a good family life, may require a less active working life. These findings align with research on older adults and how they need to negotiate and prioritise the activities they engage in (Donnellan & O'Neill, 2014; Phillips et al., 2013). Second, our participants developed meaningful bonds with new places, such as one's parents' house, or a second home, which is a finding that we did not encounter in the literature. Third, our participants found

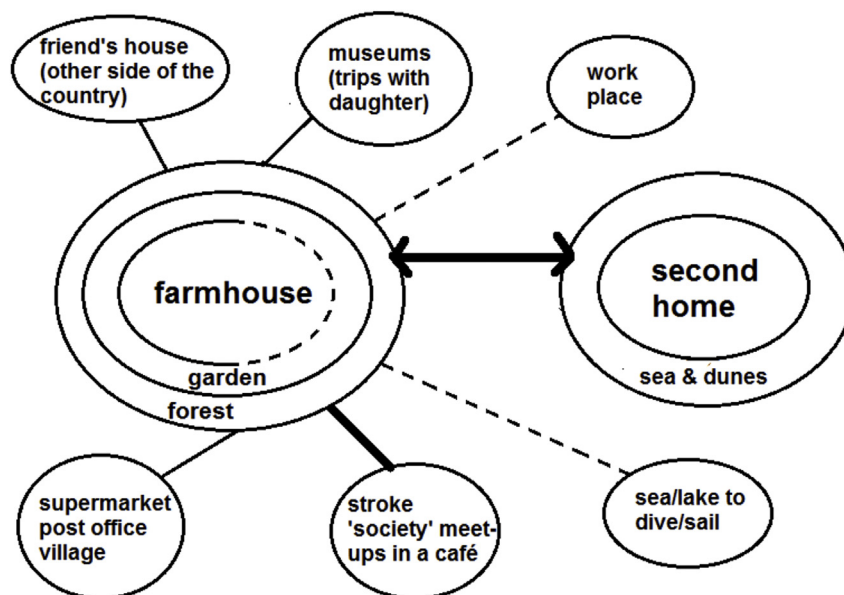


Fig. 3. Toon's place-map, with part of his farmhouse marked as inaccessible, and the second home as a new place.



new meaning in connecting to places in the home and the community: walking the dog became a way of becoming healthy and fit again; cycling on an electric bicycle was a symbol of freedom and a means that opened up the world. Finally, the idea of interplay, or reciprocity, between places emerged as very important. Different places have their own meaning and function which are closely connected to experiences of flow and disruption. For instance, the living room can be a place to socialise, a small room upstairs a place to withdraw. Furthermore, feeling well in one place (e.g. the small room upstairs) can compensate for, or help people deal with, feeling unwell in another (e.g. the living room). Finally, the idea of reciprocity between places helped to show that loss of self is not only experienced by survivors, but by significant others as well (Moore and Gillespie, 2014).

The discussion of our findings needs to be read in the context of the strengths and limitations of our study. A methodological strength of this article is the use of place-maps, which helped the participants visualise important places, the (lack of) connections between them, and how the loss of specific places was compensated for with acquiring new places. The participants were in charge of designing the map, as well as making additions and modifications. Hence, engaging in the activity could help to empower them. An important limitation to this study is that ABI is a very general category. The many differences in ABI-induced impairments, combined with differences in social context, socio-economic status, age, gender, but also personality characteristics such as self-reflection, result in the fact that it is difficult to compare between participants (see Hoogerdijs et al., 2011). In our sample, socio-economic status and place of residence may have played an important role in understandings of place. Most of our participants (15) had an average or low socio-economic status, which will have impacted their financial means to access places where they feel well. Furthermore, twelve of our participants lived in a rural area, six in an urban environment. These different places of residence may influence access to different kinds of places, such as green space, services, and places of leisure. However, it is difficult to draw definite conclusions here, because of the above-mentioned interplay with other factors.

By linking sense of self of survivors and significant others to sense of place, we brought the concept of place identity to the fore (Kyle et al., 2004). Place identity includes the values, attitudes and beliefs held by individuals in relation to places that provide opportunities to both express and affirm their identity (Bell et al., 2015). ABI survivors' sense of who they are and what defines them depends on the functional reliance on place such as the clinical, home and working place. The general experience of becoming part of the world again gains specific content by foregrounding at which places and what time they wish to (inter)act and feel part of things, and what places they might choose to avoid.

Our findings also contribute to the theoretical repertoires in the rehabilitation literature, where experiences of loss and reconstruction of self-identity are recurring themes (Beadle et al., 2016). Identity changes in these studies are related to finding one's place in the world, in the abstract sense (Levack et al., 2014). However, our study on bio-geo-graphical disruption and flow focuses on *concrete* places in the world that are meaningful for individual survivors. Through this focus, it showcased that identity confusion following brain injury, of both survivors and their intimi, can be diminished or balanced by re-enacting the articulated reciprocity between places.

These novel theoretical insights help rehabilitation professionals to shift focus from a body with lost functions that needs to be optimally recovered in the clinic, to a network of places that are relevant in ABI survivors' own living environments. It is to this living environment that ABI survivors need to feel physically, affectively, cognitively, and socially bonded again. Thinking in terms of a network of places enables professionals to deal with the complexities in community participation that ABI survivors face. Therefore, besides being a research tool, place-mapping also has the potential to be used as an intake and evaluation tool in outpatient rehabilitation practice. In this context, we are developing a digital home- and place-making tool to map the past, current

and future networks of places in the lives of ABI-survivors.

The articulated balancing and reciprocity between places may contribute to rehabilitation research, as it puts the value of validated independence and participation scales into perspective. Our study has shown that ABI survivors and their families are dealing with independence and community participation, by balancing and coordinating different ways of being independent and participative at places where they wish to (inter)act. So, in everyday life, independence and participation are neither single, coherent, factors nor clear-cut, stable goals (Harvey, 2018; Struhkamp et al., 2009).

Overall, we conclude that individual meanings ascribed to places, as well as preferences for specific places, are subject to change. Hence we argue for a shift in perspective from a changing sense of self towards a focus on a changing sense of place. Research on sense of place with ABI survivors could be expanded by applying it in relation to therapeutic landscape experiences, similar to Bell et al. (2015) in their work on therapeutic experiences of coastal landscape among healthy individuals. Such work could increase insight into the types of experiences that ABI survivors seek out, as well as how they negotiate personal challenges and achievements. Another avenue for further research is the mobility of ABI survivors. Insights into post-stroke mobility, or connections between meaningful places, could be drawn out more through use of mobile methods such as walking interviews (Lager et al., 2016). Furthermore, the role of virtual places in the renegotiation of everyday interactions with places, which was not part of the current research, is a promising avenue for further research. Especially for ABI survivors who are impaired in their physical mobility, it makes sense to assume that virtual places may become important post-ABI, and replace some of the places that have become inaccessible. Finally, it would be relevant to apply the concept of bio-geo-graphical disruption with other target groups for whom the disruption process sets in more gradually, such as dementia patients.

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## Appendix A. Supplementary data

Supplementary data related to this article can be found at <http://dx.doi.org/10.1016/j.socscimed.2018.05.005>.

## References

- American Stroke Association, 2017. About stroke. Retrieved from <http://www.strokeassociation.org>.
- Babbie, E., 2013. *The Practice of Social Research*. International Edition. Wadsworth, Belmont.
- Beadle, E.K., Ownsworth, T., Fleming, J., Shum, D., 2016. The impact of traumatic brain injury on self-identity: a systematic review of the evidence for self-concept changes. *J. Head Trauma Rehabil.* 31 (2), E12–E25.
- Bell, S.L., Phoenix, C., Lovell, R., Wheeler, B.W., 2015. Seeking everyday wellbeing: the coast as a therapeutic landscape. *Soc. Sci. Med.* 142, 56–67.
- Bury, M., 1982. Chronic illness as biographical disruption. *Sociol. Health Illness* 4, 167–182.
- Crooks, V.A., Chouinard, V., Wilton, R.D., 2008. Understanding, embracing, rejecting: women's negotiations of disability constructions and categorizations after becoming chronically ill. *Soc. Sci. Med.* 67 (11), 1837–1846.
- DeMiglio, L., Williams, A., 2016. A sense of place, a sense of wellbeing. In: Williams, A. (Ed.), *Sense of Place, Health and Quality of Life*. Taylor & Francis, Abingdon, pp. 15–30.
- Donnellan, C., O'Neill, D., 2014. Baltes' SOC model of successful ageing as a potential framework for stroke rehabilitation. *Disabil. Rehabil.* 36 (5), 424–429.
- Eilertsen, G., Kirkevold, M., Bjørk, I.T., 2010. Recovering from a stroke: a longitudinal, qualitative study of older Norwegian women. *J. Clin. Nurs.* 19, 2004–2013.
- Faircloth, C.A., Boylstein, C., Rittman, M., Young, M.E., Gubrium, J., 2004. Sudden illness and biographical flow in narratives of stroke recovery. *Sociol. Health Illness* 26 (2),

- 242–261.
- Fallahpour, M., Kottorp, A., Nygård, L., Larsson Lund, M., 2015. Participation after acquired brain injury: associations with everyday technology and activities in daily life. *Scand. J. Occup. Ther.* 22 (5), 366–376.
- Galvin, J., Froude, E.H., McAleer, J., 2010. Children's participation in home, school and community life after acquired brain injury. *Aust. Occup. Ther. J.* 57 (2), 118–126.
- Gelech, J.M., Desjardins, M., 2011. I am many: the reconstruction of self following acquired brain injury. *Qual. Health Res.* 21 (1), 62–74.
- Grace, J.J., Kinsella, E.L., Muldoon, O.T., Fortune, D.G., 2015. Post-traumatic growth following acquired brain injury: a systematic review and meta-analysis. *Front. Psychol.* 6 (1162), 1–16.
- Gracey, F., Ownsworth, T., 2011. The experience of self in the world: the personal and social contexts of identity change after brain injury. In: Jetten, J., Haslam, C., Haslam, S.A. (Eds.), *The Social Cure: Identity, Health and Well-being*. Psychology Press, Hove, pp. 273–295.
- Harvey, J., 2018. Theorising everyday life after acquired brain injury. *Disabil. Soc.* 33 (1), 78–93.
- Hennink, M., Hutter, I., Bailey, A., 2010. *Qualitative Research Methods*. Sage, London.
- Hoogerdijk, B., Runge, U., Haugboelle, J., 2011. The adaptation process after traumatic brain injury. An individual and ongoing occupational struggle to gain a new identity. *Scand. J. Occup. Ther.* 18, 122–132.
- Joffe, H., Yardley, L., 2003. Content and thematic analysis. In: Marks, D.F., Yardley, L. (Eds.), *Research Methods for Clinical and Health Psychology*. Sage, London, pp. 56–68.
- Kindon, S., 2010. Participatory action research. In: Hay, I. (Ed.), *Qualitative Methods in Human Geography*, third ed. Oxford University Press, Don Mills, pp. 259–277.
- Kirkevold, M., Martinsen, R., Arnesveen Bronken, B., Kvigne, K., 2014. Promoting psychosocial wellbeing following stroke using narratives and guided self-determination: a feasibility study. *BMC Psychology* 2 (4), 1–12.
- Kyle, G.T., Mowen, A.J., Tarrant, M., 2004. Linking place preferences with place meaning: an examination of the relationship between place motivation and place attachment. *J. Environ. Psychol.* 24 (4), 439–454.
- Lager, D., Huigen, P.P.P., Hoven, B. van, 2016. Rhythms, ageing and neighbourhoods. *Environ. Plann.* 48 (8), 1565–1580.
- Levack, W.M.M., Boland, P., Taylor, W.J., Siegert, R.J., Kayes, N.M., Fadyl, J.K., McPherson, K.M., 2014. Establishing a person-centred framework of self-identity after traumatic brain injury: a grounded theory study to inform measure development. *BMJ Open* 4, e004630.
- McCarthy, M.J., Lyons, K.S., 2015. Incongruence between stroke survivor and spouse perceptions of survivor functioning and effects on spouse mental health: a mixed-methods pilot study. *Aging Ment. Health* 19 (1), 46–54.
- Medved, M.I., Brockmeier, J., 2008. Continuity amid chaos: neurotrauma, loss of memory, and sense of self. *Qual. Health Res.* 18 (4), 469–479.
- Meijering, L., Nanninga, C.S., Lettinga, A.T., 2016. Home-making after stroke. A qualitative study among Dutch stroke survivors. *Health Place* 37 (1), 35–42.
- Meijering, L., Lettinga, A.T., Nanninga, C.S., Milligan, C., 2017. Interpreting therapeutic landscape experiences through rural stroke survivors' biographies of disruption and flow. *J. Rural Stud.* 51, 275–283.
- Moore, H., Gillespie, A., 2014. The caregiving bind: concealing the demands of informal care can undermine the caregiving identity. *Soc. Sci. Med.* 116, 102–109.
- Nanninga, C.S., Meijering, L., Schönherr, M.C., Postema, K., Lettinga, A.T., 2015. Place attachment in stroke rehabilitation: a transdisciplinary encounter between cultural geography, environmental psychology and rehabilitation medicine. *Disabil Rehabil.* 37 (13), 1125–1134.
- Nanninga, C.S., Meijering, L., Schönherr, M.C., Postema, K., Lettinga, A.T., 2017. Unpacking community mobility: a preliminary study into the embodied experiences of stroke survivors. *Disabil Rehabil.* <http://dx.doi.org/10.1080/09638288.2017.1323031>.
- Nochi, M., 1998. "Loss of self" in the narratives of people with traumatic brain injuries: a qualitative analysis. *Soc. Sci. Med.* 46 (7), 869–878.
- Phillips, J., Walford, N., Hockey, A., Foreman, N., Lewis, M., 2013. Older people and outdoor environments: pedestrian anxieties and barriers in the use of familiar and unfamiliar spaces. *Geoforum* 47 (113), 124.
- Prodinger, B., O'Connor, R., Stucki, G., Tennant, A., 2017. Establishing score equivalence of the functional independence measure motor scale and the barthel index, utilizing the international classification of functioning, disability and health and rasch measurement theory. *J. Rehabil. Med.* 49, 416–422.
- Schipper, K., Visser-Meily, J.M.A., Hendrikx, A., Abma, T.A., 2011. Participation of people with acquired brain injury: insiders perspectives. *Brain Inj.* 25 (9), 832–843.
- Struhkamp, R., Mol, A., Swierstra, T., 2009. Dealing with in/dependence: doctoring in physical rehabilitation practice. *Sci. Technol. Hum. Val.* 34, 55–76.
- Trexler, L.E., Trexler, L.C., Malec, J.F., Klyce, D., Parrott, D., 2010. Prospective randomized controlled trial of resource facilitation on community participation and vocational outcome following brain injury. *J. Head Trauma Rehabil.* 25 (6), 440–446.
- WHO, 2006. *Neurological Disorders: Public Health Challenges*. World Health Organisation, Geneva.